# NORTH COUNTY July 2022 www.NCPSG.org PARKINSON'S SUPPORT GROUP



#### A NEWSLETTER FOR EVERYONE AFFECTED BY PARKINSON'S IN NORTH SAN DIEGO COUNTY

#### **Recent Advances in Parkinson's Research**

#### Al to Detect Cancer May Also Spot Parkinson's

Mount Sinai researchers have developed an artificial intelligence algorithm to help detect prostate and breast types of cancers in cells. (An Al algorithm is a process that can manage lots of data at one time, and apply a set of rules to the data to provide desired information or actions.) These algorithms have been shown to also spot the early stages of Parkinson's Disease before severe symptoms appear. PreciseDx uses the technique to examine tissue samples to predict the likelihood of tumors, but when examining samples of salivary glands have detected Lewy bodies, an indicator of Parkinson's. The results have been sufficiently noteworthy to attract funding from the Michael J Fox Foundation. The system may provide a new diagnostic tool to guide early treatment decisions.

#### Miniature DBS Clinical Trials in the UK

Deep Brain Stimulation has a long history of success in treating the motor symptoms of PD. Now a new ultra-miniaturized device is being tested in clinical trials in the UK. Unlike current systems there are no leads to a battery pack and controller in the chest. All the systems are located in a small pocket created in the skull. This device is less invasive than current systems, and takes less time to install. Although the device is currently only available in the UK as a clinical trial, we are certain that our American providers will be inspired to create similar devices using advances in battery technology.

#### Spotting Parkinson's in Your Face?

Well, this is different! The European Patent Office has nominated Erin Smith, age 22 of the USA as a finalist in the *Young Inventors* prize for her Al-powered app that enables early detection of Parkinson's disease. Her app, called FacePrint, uses facial recognition and Al techniques to review expressions in the faces of potential patients. A large trial at Stanford Medical School was shown to predict Parkinson's with a 95% accuracy. The technique was developed when Erin noticed that videos of the face of Michael J Fox would display a smile that appeared emotionally distant, even when the emotion was sincere. That's the "masking" symptom that many patients display. Al techniques allow the many subtle variations in facial expression to be quantified. The intent is to release the App as a product in the near future.

#### Other News on PD Research

Where can you find the latest in Parkinson's research? The items above were curated from the Davis Phinney website's "What's new in Parkinson's" page. For the latest news, month by month, please see <a href="https://davisphinneyfoundation.org/category/research/">https://davisphinneyfoundation.org/category/research/</a>. Also see our page 4

article.

#### **Last Call for the Summer Social**

Please join us at Shadowridge Golf Club on Wednesday, July 27th at 11:30 AM for our annual summer Social. The club is located in Vista at 1980 Gateway Drive in Vista, 92081. Your reservation and menu choice are required by Friday July 22nd. See the last page for a reservation form. Make your choices and get it in today!

#### Inside This Issue

• Events Calendar Page 2

• IN FOCUS: Victoria Helms

Page 3

• 23andMe and PD Page 4

#### **Support Group Meetings**

Attendance at NCPSG in-person events requires full vaccination or natural immunity (recovered from infection) against COVID-19. Attendance at an in-person event constitutes your certification of full vaccination or natural immunity.

#### **Chapter Meetings**

#### **RANCHO BERNARDO**

#### No Meeting in July

Meetings resume on the 1st of August when the topic will be the "Big and Loud" exercise program **San Rafael Catholic Church** 17252 Bernardo

Center Road, San Diego, 92128

Hosts: Brigit King & Carol Maher

hcmaher@cox.net or 760-749-8234

#### LA COSTA CARLSBAD

#### Wednesday July 6, 1:00 PM

Speaker: Gus Fernandez, Doctor of Pharmacy Topic: "You Need A Pharmacist On Your

Parkinson's Team"

#### **Christ Presbyterian Church**

7807 Centella St Carlsbad 92009

Host: Sam Cooper NCPSGLC@gmail.com

or 520-820-0339

#### **OCEANSIDE**

#### Wednesday July 13, 1:00 PM

Speaker: Ingrid Johnson, MA, Rock Steady Boxing Topic: "Fitness Training to Strengthen PwP thru Non-contact Exercise"

First Presbyterian Church

2001 S. El Camino Real, Oceanside 92054, at Fire Mountain Rd

Host: Paul Dawson paul@video-fire.com

or 760-497-1200

#### **FALLBROOK**

#### Friday July 22, 10:00 AM

Speaker: Dr. Timothy Murphy

Topic: "Ambiguous & Anticipatory Loss, Grieving

Someone Living and Ways to Cope"

Fallbrook Wellness Center

1636 E. Mission Rd, Fallbrook 92028 Host: Irene Miller NCPSGF@gmail.com

or 760-731-0171

#### **Social Groups**

Join us for our Summer Social at Shadowridge Golf Club on Wednesday July 27, 11:30. See the registration form on the last page or contact Social Chair Sam Cooper at scprphd@gmail.com or 520.820.0339

#### **NCPSG Board of Directors**

**Wednesday July 20, 1 - 3 PM** Board meets online on the third Wednesday of the month. Paul Dawson 760-497-1200

#### **Physical Exercise**

(Contact Provider for In-person or On-line Options. Fees May Be Charged)

**ROCK STEADY BOXING -** Improve Parkinson's quality of life through non-contact boxing-based fitness curriculum. In-gym and online classes available. Find a class at:

https://www.rocksteadyboxing.org/

PERSONALLY FIT ONLINE - Zoom classes for PD. Personallyfitonline.com or contact Doris Flood, PT at dflood@personallyfitonline.com

**CEREBRAL MOTION** Specialized personal training for PD. <u>Cerebralmotion.com</u> or contact Mickey Burke MS at <u>mickey@cerebralmotion.com</u>

**COACH ME STRONG** A one-on-one exercise coaching program. Email <u>Coachmestrong.com</u>

#### **SmartXPD Online Exercise with Patrick**

An online/video exercise community. See SmartXPD.com or contact patrick@smartxpd.com

**Don Skaggs Total Healthworks**: Evidence based online fitness program. Email totalhealthworks.com

#### **Vocal Exercise**

**Tremble Clefs -**Therapeutic Singing and Socializing. *North Inland Chapter (Rancho Bernardo)* 

Wednesdays at 10:00 AM

San Rafael Catholic Church in the Parish Hall, 17252 Bernardo Center Road, San Diego 92128 North Coastal Chapter (Encinitas)

Tuesdays at 1:00 PM

Bethlehem Lutheran Church, in the Youth Multi Use Center, 925 Balour Dr, Encinitas, CA 92024

In-person participants should be fully vaccinated, or attend via Zoom. Contact Matt Ignacio for details.

Email: matt.sdtrembleclefs@gmail.com

Website: <a href="https://www.trembleclefs.com/">https://www.trembleclefs.com/</a> Facebook: <a href="https://www.facebook.com/TrembleClefsSD">https://www.facebook.com/TrembleClefsSD</a>

**AudAbility -** Professional music therapy program for People with Parkinson's.

Check the website to see if you are eligible for special subsidies for North County residents for this program.

MusicWorx.com. Or Cassandra Richtsmeier 858-457-2201 or <a href="mailto:crichtsmeier@musicworxinc.com">crichtsmeier@musicworxinc.com</a>



"I was a Navy brat. We moved all over the US. I attended 12 schools in 12 years and learned how to be the 'new kid' in class. It made me sensitive to new aspects of life and understand that things change. After graduating from UCLA and earning my teaching credential, I had a career in the classroom and am very thankful for those meaningful and productive years. I enjoy reading good fiction, riding my bicycle, running, and attending CrossFit classes five times a week."

"When my husband, Jim, was diagnosed with Parkinson's things changed. There is a big learning curve. You continue to learn as the Parkinson's Journey unfolds. You make adjustments to your life's daily routines. We

have attended the Fallbrook support group chapter for about three years. The speakers are very informative, but the breakout groups are particularly helpful. Fellow Care Partners are able to offer support and real life suggestions. It is wonderful to be with others that truly understand the real life issues of living with Parkinson's."

"Our family is incredibly supportive. They visit often and ask Jim to make a list of projects that he wants done around the house and often work with Jim. He really enjoys being with them and getting things done. Friends and neighbors frequently offer help, but so far we have not had to call on them too often. But it's good to know they're there and I really appreciate the backup."

"We have attended the Fallbrook support group chapter for about three years.
The speakers are very informative, but the breakout groups are particularly helpful.

"It is wonderful to be with others that truly understand the real life issues of living with Parkinson's."

"Don't focus on what you can't do together anymore. Focus on what you can still do together and then do it."

"One of the positives about our Parkinson's Journey is it has reunited us with some couples in the area where the husband has Parkinson's and the wives are Care Partners. These are couples in long term relationships. It is wonderful to be around such caring couples. We all really enjoy each other's company and feel very comfortable being together."

"Be patient with your loved one. Our Parkinson's partners are giving us everything they have. They want to continue to enjoy life and want us to continue to enjoy life. Don't focus on what you can't do together anymore. Focus on what you can still do together and then do it."

#### **NCPSG Notices**

**We provide information** in our newsletter and chapter meetings on a broad array of Parkinson's-related topics and perspectives. **A presentation should not be interpreted as our endorsement**. Do your own research, and talk with your neurologist before taking action.

**We take photos and videos** at our meetings and events and may use them in our promotional materials. Please tell the event leader if you do not want your image to appear.

#### Did you know?

If you are receiving this newsletter electronically you can click on the links and be taken directly to the resource. To switch to electronic delivery contact Micheline at <a href="mailto:ncpsgcs@gmail.com">ncpsgcs@gmail.com</a> or Caryl at <a href="mailto:carylparrish@gmail.com">carylparrish@gmail.com</a>. If you find a broken link, contact Rex at <a href="mailto:ncpsgnl@gmail.com">ncpsgnl@gmail.com</a>.

#### 23andMe and Parkinson's

One promising way to research the heritability and effects of Parkinson's (or any other) Disease is to gather information from large numbers of symptomatic persons. The genetics testing company 23andMe has teamed up with the Michael J Fox Foundation to provide large anonymized (stripped of individual identification) data sets to approved researchers.

The way it works is for subscribers to submit genetic materials to 23andMe for testing to receive health and ancestral information. Subscribers also have an opportunity to join projects and fill out surveys on their particular health characteristics, and to consent to share the anonymized information with the database. The information is provided by 23andMe to MJFF who hosts the data in the Fox Insight Data Exploration Network (Fox DEN). The DEN is made available to various approved research projects. This is believed to be the world's largest data set for Parkinson patient information available to researchers.

For more information see <a href="https://www.23andme.com/">https://www.23andme.com/</a> or their PD research YouTube webinar at <a href="https://www.youtube.com/watch?v=GtCGsOGf2ck">https://www.youtube.com/watch?v=GtCGsOGf2ck</a>. Also see MJFF's information at <a href="https://www.michaelifox.org/webinar/whats-your-dna-understanding-parkinsons-genetics">https://www.michaelifox.org/webinar/whats-your-dna-understanding-parkinsons-genetics</a>, or their DNA webinar at <a href="https://www.youtube.com/watch?v=wUBO7Ewsv1U">https://www.youtube.com/watch?v=wUBO7Ewsv1U</a>.

#### **Passings**

- Tom Glaze
- Karen Cohen
- Len Nair

Our thoughts & prayers go out to family & friends

To update or remove your contact info, please let **Micheline Allen** know. 760-631-0649 <a href="mailto:ncpsqcs@gmail.com">ncpsqcs@gmail.com</a>

Our mailing address:

**NCPSG** 

PO Box 230566

**Encinitas CA 92023** 

**Our Website: (Donations accepted)** 

NCPSG.org

Our Facebook page: (Donations accepted, no fees)

https://m.facebook.com/NorthCountyParkinsonsSupportGroup/

## NEUROLOGY CENTER OF SOUTHERN CALIFORNIA

CONTACTS

General Email Contact <u>info@ncpsg.org</u>

**Rancho Bernardo Support Group Leaders** 

Carol Maher <u>hcmaher@cox.net</u>

760-749-8234

Brigit King <u>bkicedancer@gmail.com</u>

858-354-2498

La Costa Support Group Leader

Sam Cooper <u>NCPSGLC@gmail.com</u>

520-820-0339

La Costa Co-leaders

Art Braun <u>artjbraun@hotmail.com</u>

760-550-0508

Bill Farrington <u>billfarr48@gmail.com</u>

760-815-5234

Oceanside Support Group Leader

Paul Dawson <u>paul@video-fire.com</u>
NCPSG Board President 760-497-1200

Oceanside Co-Leader, Library

Madonna Bingham <u>granny6mb@gmail.com</u>

760-757-7564

**Fallbrook Support Group Leader** 

Irene Miller <u>NCPSGF@gmail.com</u>

760-731-0171

Fallbrook Support Group Co-Leader

Open

Treasurer, Recording Secretary & Webmaster

Caryl Parrish <u>carylparrish@gmail.com</u>

760-753-5004

Corresponding Secretary <a href="mailto:ncpsgcs@gmail.com">ncpsgcs@gmail.com</a>

Micheline Allen 760-631-0649

Social Director <u>scprphd@gmail.com</u>

Sam Cooper 520-820-0339

Video Documentation Google: Arthur Bierle on Vimeo

Arthur Bierle 760-749-2182

**Board Member Emeritus** 

Thelma Balbes

Newsletter

Publisherpaul@video-fire.comPaul Dawson760-497-1200

Editor <u>ncpsgnl@gmail.com</u>

Rex McCoy 760-519-9588

Focus Interviews scprphd@gmail.com

Sam Cooper 520-820-0339

Printed Edition Distribution granny6mb@gmail.com
Madonna Bingham 760-757-7564

Electronic Distribution carylparrish@gmail.com

## North County Parkinson's Support Group

### **Summer Social**

#### Wednesday July 27th, 11:30 AM

#### **Shadowridge Golf Club**

1980 Gateway Drive, Vista 92081

\$20.00 per ticket

φ20.00 per tionet
Menu Choices (indicate # in the space):
Chicken Cobb Salad
French Dip Sandwich
NCPSG requires all attendees be COVID vaccinated or naturally immune. I/we acknowledge
Please Print
Name(s)

We must receive your reservation by Friday, July 22nd.

Mail this form to and check made out to NCPSG:

NCPSG PO Box 230566 Encinitas, CA 92023

Your phone number